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ABSTRACT

This study examined the incidence and nature of abuse of individuals with developmental disabilities residing with their families in New York State. Informal meetings were held with service providers to discuss the issues, and 84 allegations of familial abuse and neglect were reviewed. The study found that familial abuse of these individuals constitutes about 9% of all reports of alleged abuse and neglect filed by state-operated and state-certified residential and day programs serving persons with developmental disabilities. The most typical alleged victim was a young woman under 35 who was attending a day program and living at home. The alleged perpetrators were more likely to be male, and most were identified as a parent or other quasi-parental figure. Of the service providers that responded to a survey concerning their role in 1 or more of the 84 cases, over half indicated that they were less than fully satisfied with their ability to investigate the allegations. Approximately one-fourth of the reporting programs contacted law enforcement officials for help, while 66% contacted the local Adult Protective Services for help. Only 22% of those requesting adult protective services assistance were totally satisfied with help received. There was a higher likelihood of physical injury to the alleged victims in the familial reports, and victims were likely to be involved in multiple reports of abuse. Recommendations are presented which would clarify the responsibility for conducting investigations into allegations of familial abuse; develop close cooperative relationships between local social service districts and developmental disabilities service offices; reaffirm the reporting responsibilities of provider agencies; ensure the availability of emergency respite and short-term residential options; and provide primary prevention services including parent training. An appendix presents responses to the report from two New York government agencies. (JDD)

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A Review of Familial Abuse Allegations of Adults With Developmental Disabilities

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A Review of Familial Abuse Allegations of Adults With Developmental Disabilities

State of New York
Commission on Quality of Care
for the Mentally Disabled

July 1992

Preface

The study revealed that, while the incidence of familial abuse of persons with developmental disabilities is low, it nevertheless constitutes about 9% of all reports of alleged abuse and neglect filed by state-operated and state-certified residential and day programs serving persons with developmental disabilities. . . . these alleged victims are also much more likely to be involved in multiple reports of abuse.

In response to numerous problems that had been called to its attention by providers, family members and advocates, the Commission undertook this study of the nature and incidence of abuse of individuals with developmental disabilities residing with their families. These problems ranged from the absence of clear responsibility for investigations, to unclear statutory authority for intervention, to the absence of adequate services to assist both the developmentally disabled person and the family. The Commission's own experience in investigating tragic deaths that were the products of abuse and neglect in family settings[1] reinforced the importance and validity of the concerns being expressed.

This study shed important light upon a subject about which there has been little more than anecdotal information. It revealed that, while the incidence of familial abuse of persons with developmental disabilities is low, it nevertheless constitutes about 9% of all reports of alleged abuse and neglect filed by state-operated and state-certified residential and day programs serving persons with developmental disabilities. At the same time, it found that there is a higher proportion of alleged physical and sexual abuse among these reports than those emanating from other residential settings. There is also a higher likelihood of physical injury to the alleged victims in these reports. Most importantly, the study found that these alleged victims are also much more likely to be involved in multiple reports of abuse.

The findings of the study have clear implications for preventive and remedial actions that must be taken. In the recommendations included with the report, the Commission has suggested a number of actions to:

- clarify the responsibility for conducting investigations into allegations of familial abuse;
- develop close cooperative relationships between local social service districts and developmental disabilities service offices in carrying out responsibilities for investigations, risk assessments and the development and implementation of protective services plans;

[1] See NYS Commission on Quality of Care Reports: *In the Matter of Francis Helms (Community Hospital of Western Suffolk)*, June 1989; and *In the Matter of Jerry Smith – A Resident of Fulton County*, May 1984.

- reaffirm the reporting responsibilities of provider agencies and involve them in the development and implementation of protective services plans;
- ensure the availability of emergency respite and short-term residential options in each OMRDD local service area; and,
- provide primary prevention services including parent training to cope with the special challenges of raising children with developmental disabilities.

We are pleased to note that the Commissioners of the Department of Social Services and the Office of Mental Retardation and Developmental Disabilities concur in the need to address these issues and have agreed to institute actions to implement the recommendations.

The findings, conclusions, and recommendations of the report reflect the unanimous opinion of the Commission members. Responses to a draft of this report from the New York State Department of Social Services and New York State Office of Mental Retardation and Developmental Disabilities are attached as Appendix A.

Clarence J. Sundram, Chairman

Elizabeth W. Stack, Commissioner

William P. Benjamin, Commissioner

Table of Contents

Introduction 1

Major Findings 5

Adequacy of Investigations and Protective Actions 15

Conclusions and Recommendations 25

Appendix A: Responses to the Draft Report by

- NYS Department of Social Services
- NYS Office of Mental Retardation and Developmental Disabilities

Literature Review Bibliography

List of Figures

Figure 1: Demographic Characteristics of the Alleged Victims 5

Figure 2: Demographic Charactistics of the Alleged Perpetrators 6

Figure 3: Seriousness of Abuse and Neglect Allegations 7

Figure 4: Examples of Reported Allegations 8

Figure 5: Reported Investigative Outcome 10

Figure 6: Familial Issues Contributing to Abuse/Neglect Allegations 11

Figure 7: Reporting Agencies' Satisfaction With Their Ability to Investigate the Allegation 15

Figure 8: Protective Actions Taken 20

Figure 9: Reporting Agencies' Satisfaction With Their Ability to Protect the Alleged Victim 22

Figure 10: Limited "Safety Nets" 23

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Introduction

In accordance with its statutory mandate to ensure the effective investigation of all allegations of abuse and neglect filed by state-operated and/or -licensed mental health and mental retardation residential and outpatient programs (MHL §45.07[c]), the Commission's statute requires that all such programs file these reports with the Commission within three working days of their discovery. Approximately 4,000 reports are filed annually with the Commission — about half of which are filed by mental health programs (46%), and about half of which are filed by mental retardation programs (54%).

One out of every four abuse and neglect reports filed by mental retardation day programs relates an allegation of familial abuse or neglect.

The vast majority of these reports describe incidents which occur while the alleged victim is engaged in activities or services sponsored by the reporting program or agency and involve a program employee as the alleged perpetrator. Only 5% of these reports relate an allegation of familial abuse or neglect by a member of the family or household where the victim resides.[1]

Among reports filed by mental retardation programs, however, familial abuse reports are more common, representing approximately 10% of all reports filed, and these reports are especially common among reports filed by mental retardation day programs. *One out of every four abuse and neglect reports filed by mental retardation day programs relates an allegation of familial abuse or neglect.*

In reviewing these familial abuse and neglect reports, the Commission found that many providers cited these allegations as the most troubling reports they handle. Providers stated that these allegations are often more serious in terms of the actual harm or risk of harm to the alleged victim and that they are often the most difficult to investigate and/or resolve. Providers also reported, in a number of cases, that the alleged abuse or neglect had been ongoing or recurring.

[1] Of note, existing regulatory standards (14 NYCRR §624) do not explicitly require certified mental health or mental retardation programs to report allegations of familial abuse and neglect. These standards were drafted with a focus on allegations involving individuals enrolled in these programs and incidents which occur during program activities and events. In practice, many providers have interpreted the regulatory standards to subsume a reporting requirement for allegations of familial abuse and neglect which come to a provider's attention, but some have not.

The Commission has also had experiences investigating unusual deaths of persons with mental disabilities which have confirmed that local Adult Protective Services agencies and mental health and mental retardation programs, which are aware of the abuse or neglect of an adult with mental disabilities by family members or surrogate family care givers, often have difficulty in responding effectively to stop the abuse.[2] The Commission has witnessed a number of similarities in these cases, including the untimely investigation of complaints by local mental health and mental retardation officials, failure of local Adult Protective Services agencies to respond effectively, and poor communication and working relationships with local law enforcement officials.

The study of familial abuse and neglect of adults with developmental disabilities is a relatively uncharted area.

Based on the concerns of treatment providers and its own experience that allegations of familial abuse and neglect involving adults with developmental disabilities are often not well-handled by community agencies, the Commission concluded that a systemic study of a sample of these cases was warranted.

Review of the Literature

One of the initial steps taken by the Commission was to review the previous research on this topic. This search revealed that the study of familial abuse and neglect of adults with developmental disabilities was a relatively uncharted area. Available studies tend to focus on issues of family stress and psychological distress, but the authors of these reports typically do not mention, or even imply, that these circumstances are abusive or neglectful.

The greater difficulties associated with parenting young adults with developmental disabilities, however, are referenced in the literature.

More recently, the greater difficulties associated with parenting young adults with developmental disabilities, however, are referenced in the literature. For example, a number of researchers have examined the hypothesis that the transition to young adulthood is a particularly stressful period for families. This research has tended to confirm that the termination of school programs, the uncertainty of the young person's potential for independence, and the likelihood of the need for prolonged care, as well as the aging of caregivers, all increase family stress at this transitional time (Black, et al., 1990; Konanc and Warren, 1984; and Wikler, 1986).

[2] *In The Matter of Francis Helms*, NYS Commission on Quality of Care, June 1989; *In the Matter of Jerry Smith*, NYS Commission on Quality of Care, May 1984.

Many other researchers have sought to identify the factors that best predict increasing levels of family stress and difficulties associated with parenting individuals with developmental disabilities. Most of these researchers have focused on parenting studies of young children (Dyson, 1991; Frey, 1989; and Sherman, 1988). These studies have consistently indicated that parental perceptions of their own caregiving competence, their ability to assist their child in gaining skills for independence, and formal and informal support networks for parents are associated with less family stress and fewer family crises which are often associated with a decision to place the child out of home.

Providers clarified that it is often difficult to obtain access to families to conduct investigations, that the alleged victim is frequently reluctant for the provider to take any action, that law enforcement officials usually do not want to get involved, and that working with local Adult Protective Services and Borough/ District Developmental Disabilities Services Offices staff is often not successful.

Seltzer and Krauss found similar factors associated with maternal stress in families caring for adults with developmental disabilities. In their study, the mothers who felt more burdened perceived their families to be less cohesive, more conflicted, less independent, less likely to be involved in recreational activities, and less likely to be involved in smaller informal support networks (Seltzer and Krauss, 1989).

Haseltine and Miltenberger, in one of the few published reports centering on self-protection training for adults with developmental disabilities, acknowledged that their training model was particularly unsuccessful in addressing self-protection in abusive situations involving an individual known to the person with developmental disabilities. They state in their report that they intentionally did not include the possibility of family member or friend perpetrators of abuse, as they feared this may have traumatized their clients and/or jeopardized the trainers' relationships with the families (Haseltine and Miltenberger, 1990).

The Commission's review indicated that Haseltine and Miltenberger are not alone in their unwillingness to confront issues of familial abuse and neglect more directly. Although the literature fairly well documents the risk factors of families and increasingly recognizes that these factors intensify as children grow from adolescence to young adulthood, not a single empirical study of the incidence and nature of familial abuse and neglect of adults with developmental disabilities was found.

Methodology

The agency began the planning of its study by holding meetings with downstate and upstate mental retardation service providers to discuss the issues and concerns surrounding their familial abuse and neglect reports, and the problems they encounter in investigating these allegations and in providing protection for the alleged victims. These meetings were extremely helpful. Individual providers clarified that it is often difficult

to obtain access to families to conduct investigations, that the alleged victim is frequently reluctant for the provider to take any action, that law enforcement officials usually do not want to get involved, and that working with local Adult Protective Services and Borough/District Developmental Disabilities Services Offices (B/DDSO) staff is often not successful. Perhaps most important, many providers indicated that they believed they had little to offer in substantial relief or support services for the individual or the family and that, in particular, they usually had no other residential options available.

The Commission conducted a more formal review of the 84 allegations of familial abuse and neglect which had been reported to the Commission during the six-month period, July 1989-December 1989.

Using these informal meetings as a backdrop, the Commission conducted a more formal review of the 84 allegations of familial abuse and neglect which had been reported to the Commission during the six-month period, July 1989 - December 1989. In addition to reviewing the initial reports of these allegations and the investigation summaries which the reporting programs had submitted to the Commission, the Commission also surveyed each of the reporting programs, asking for additional information about the allegations, their intervention efforts, and the roles of law enforcement, Adult Protective Services, and the B/DDSO in addressing the cases. In total, the Commission received completed survey forms from the reporting programs for 70 of the 84 allegations in the sample, or 83% of the cases.

Finally, for a number of the variables studied, the Commission was also able to compare data related to the 84 sample reports of familial abuse or neglect with the data pertaining to all reports of alleged abuse and neglect filed by state-operated and -licensed mental retardation programs for the same period (n = 863). This analysis revealed a number of interesting differences in the familial and non-familial reports, which further contributed to our observations.

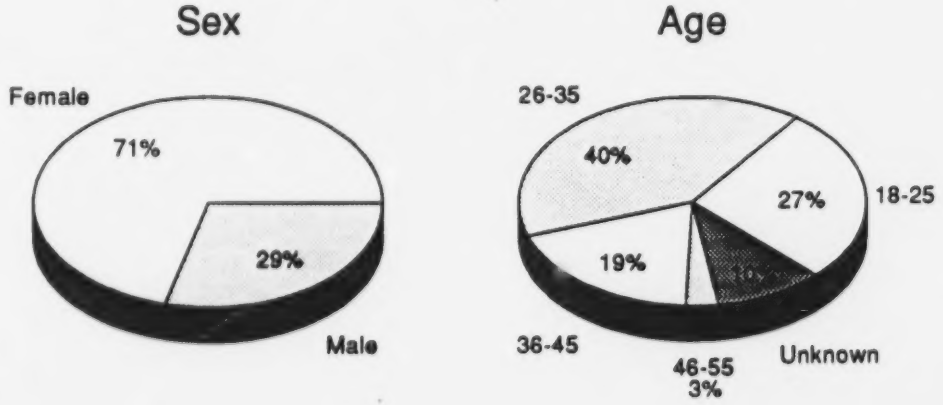
Major Findings

Women and Young Adults at High Risk

Review of the 84 allegations indicated that the most typical alleged victim was a young woman under 35 who was attending a day program and living at home (Figure 1). In total, 71% of the alleged victims were female; 67% were 35 years of age or younger; and 80% were currently enrolled in a day program and living at home. Of the alleged victims not living at home, almost all were living in community residences.

Interestingly, this profile of the alleged victims in familial abuse cases differed markedly from the profile of alleged victims in non-familial abuse reports filed with the Commission by mental retardation programs during the same period. In these cases, only 46% of the alleged victims were females, and less than half (47%) were 35 years of age or younger.

Figure 1: Demographic Characteristics of the Alleged Victims
[N = 84 Reports]



Alleged Perpetrators Often Parents/ Stepparents

Unlike the alleged victims, the alleged perpetrators in the familial reports were more likely to be male (58%), and most were identified as a parent, stepparent, or other "quasi" parental figure (70%) (Figure 2). Fathers were identified as alleged perpetrators in 29% of the allegations, and stepfathers and mothers' boyfriends were identified in an additional 12% of the cases. Mothers were also identified as alleged perpetrators in 29% of the cases, but there were no cases which implicated a stepmother or father's girlfriend. Siblings were identified as alleged perpetrators in nearly one-fifth of the cases (sisters in 8% and brothers in 11%).

Figure 2: Demographic Characteristics of the Alleged Perpetrators
[N = 84 Reports]

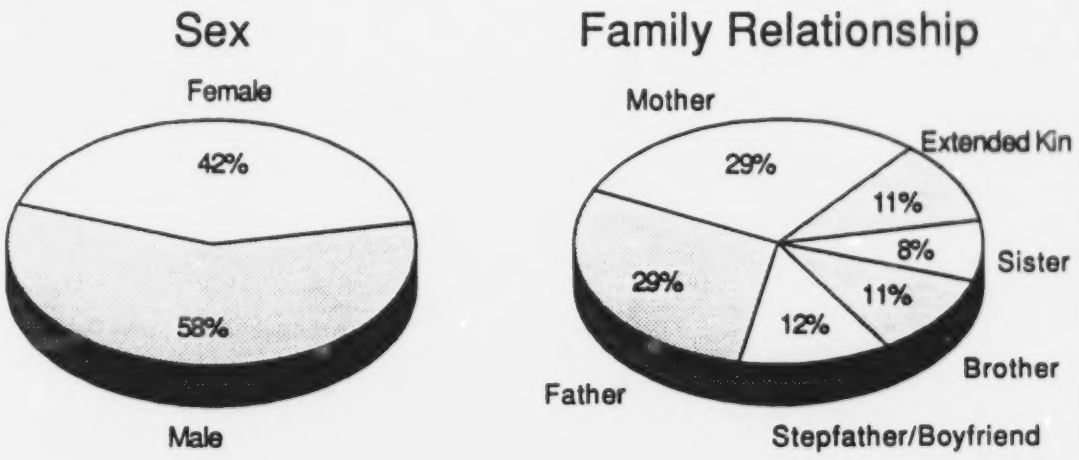


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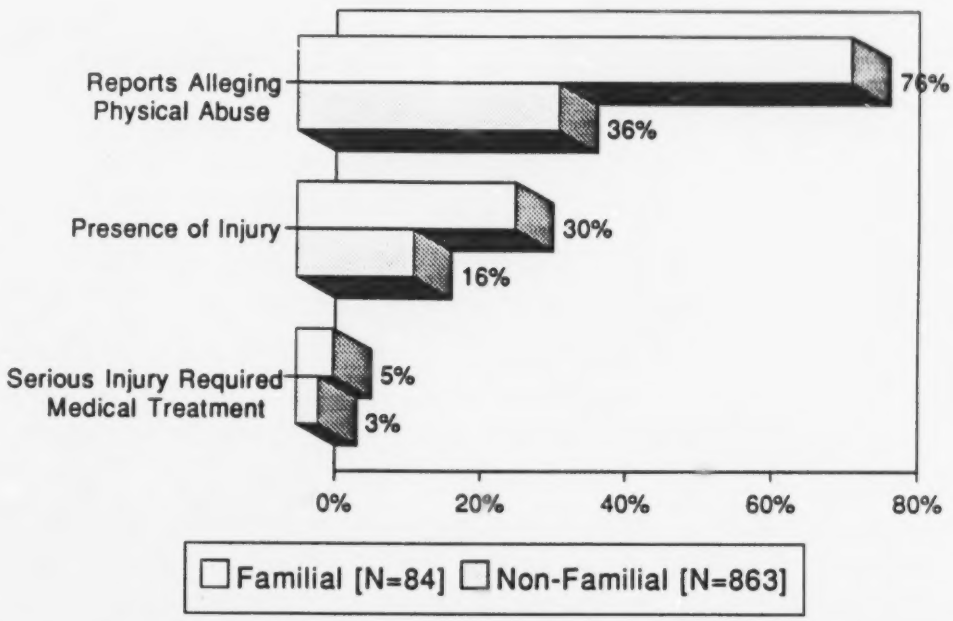
Figure 3: Seriousness of Abuse and Neglect Allegations



Many Allegations Were Serious

As compared to the non-familial abuse and neglect reports filed by mental retardation programs over the same period, the familial abuse reports appeared more serious (Figure 3). There was a much higher incidence of physical abuse allegations in the familial versus non-familial reports (76% versus 36%), and the familial reports studied were nearly twice as likely as the non-familial reports to involve a physical injury (30% versus 16%). Familial reports were also slightly more likely than non-familial reports to involve a serious injury requiring medical treatment by a physician or treatment in an emergency room or a hospital (5% versus 3%).

The injury rate in the reports of familial abuse also reflects the relatively high "violence" rating of many of the allegations. As reflected in Figure 4, many allegations involved slaps or shoves, but others involved considerably more aggressive acts.

Figure 4: Examples of Reported Allegations

- The day program staff called the young woman's (age 24) home to inquire as to why she was not at program. The woman's mother reported that her daughter was destroying property and banging her head. When the staff arrived to transport the woman to program, they found her tied to a chair. When staff released the young woman, they discovered deep red marks around both wrists. (Substantiated)*

- A young woman (age 22) complained of vaginal discomfort and alleged that her mother's boyfriend had touched her breasts and genital area. (Inconclusive)*

- A young man (age 19) alleged that he had a fight with his sister, prompted by her request that he go to bed so that she could clean the living room. When he resisted going to bed, his sister allegedly hit him on the foot with a broom and pushed him, resulting in her brother falling over the couch and hitting his head. The young man arrived at his day program with bruises on his arm and open wounds on the back of his head and ankle. (Substantiated)*

- The staff noticed that one of the women (age 28) attending the workshop had a swollen area below her right eye. In an interview, the woman alleged that her brother had hit her the previous evening because she had refused "to do something he wanted me to do." (Inconclusive)*

- A young woman attending a day program alleged that her father had been drinking over the weekend and he entered her bedroom and began fondling her breasts. (Substantiated)*

- A male program participant (age 31) arrived at day program with a large bruise on his forehead. He reported that his mother had not come home over the weekend and he had not eaten in two days. (Substantiated)*

- Upon arriving at day program, the staff noticed that a female program participant (age 27) had bruises on her upper right arm. The young woman alleged that her mother had hit her with a belt. The young woman's mother reported that she frequently hits her daughter with a belt to protect herself and her son from her daughter's aggressive outbursts. (Substantiated)*

- A 27-year-old young man reported that his father had slapped him, punched him in the stomach, and kicked him in the buttocks for losing his dentures. The father admitted to hitting his son. (Substantiated)*

- Upon returning from a home visit, a young man (age 23) who was residing in a community residence alleged that his father and his father's friend had sexually fondled him. (Inconclusive)*

- A young woman (age 26) alleged that her father had kicked her after she refused to do what he asked. (Substantiated)*

*Denotes reporting agency's investigation determination of the report.

Additionally, one-fourth of the familial abuse reports studied related allegations of sexual abuse, and it appeared that females were particularly vulnerable to this type of allegation. Although there was little difference in the percentage of male and female victims involved in reports relating physical abuse allegations (72% versus 75%), female alleged victims were much more likely to be involved in sexual abuse allegations (30% versus 8%). In 8 of these 20 sexual abuse reports, the allegation involved intercourse with the reported victim, while in the remaining cases, the allegation centered on inappropriate touching or fondling of the alleged victim.

As compared to non-familial reports, the analysis also showed that a much smaller percentage of the familial reports involved the generally less serious allegations of verbal abuse (7% versus 21%).[3]

With very few exceptions, the alleged incidents occurred within the privacy of the family home (93%), where there were no witnesses other than the alleged victim and the family.

Few Witnesses

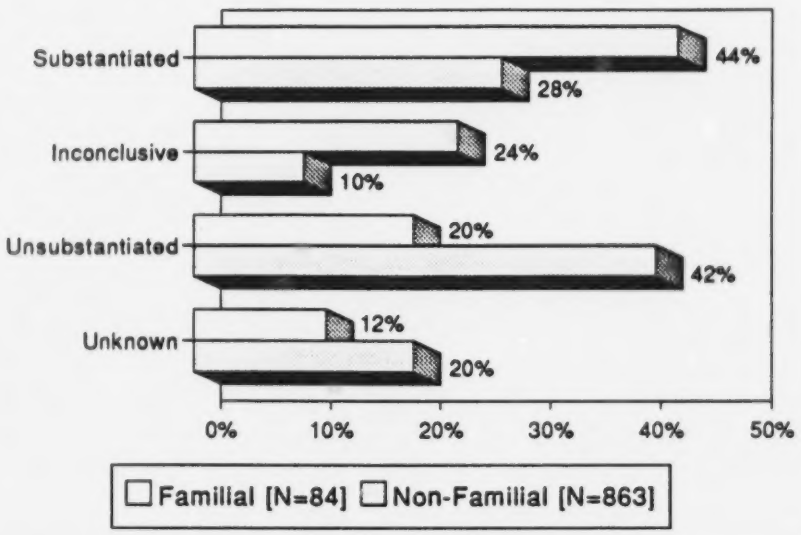
With very few exceptions, the alleged incidents occurred within the privacy of the family home (93%), where there were no witnesses other than the alleged victim and the family. This characteristic of the cases was often particularly critical to their ultimate resolution and investigation. Nearly one-fifth (19%) of the reporting programs who responded to the Commission's survey cited the lack of witnesses outside the family and/or the alleged victim's inability to report consistently as factors impeding their investigations. Additionally, investigations of 24% of the 84 reports were closed with an "inconclusive" finding by the reporting program—many times with an explanation that there were no witnesses outside the family.[4]

In three-fourths (76%) of the reports, the alleged victim was also the initial reporter. In most cases, the individual told the day program staff. In another 14% of the cases, the initial reporter was a staff person, who had either directly witnessed the abusive incident or who discovered the alleged victim's injuries. Interestingly, in 10% of the reports, a family member was the initial reporter. In almost all of these cases, a parent recounted the abusive incident in the context of describing an acting-out episode of the alleged victim at home to a program staff person.

[3] Total percentages of the types of allegations cited in the 84 reports exceed 100% because many reports related two or more different types of allegation.

[4] Of note, only 10% of the non-familial reports filed with the Commission by mental retardation agencies for the same time period were closed with a finding of "inconclusive."

Figure 5: Reported Investigative Outcome
[N = 84 Reports]



High Confirmation Rates

Based on the reporting programs' investigations of the cases, the familial abuse and neglect reports also had a significantly higher "confirmation" rate than non-familial reports filed by mental retardation programs over the same period (Figure 5).[5] Forty-four (44) percent of the familial abuse allegations were confirmed versus only 28% of the non-familial reports. Additionally, as noted above, an unusually high 24% of the familial abuse allegations were closed with a finding of "inconclusive" by the reporting program. "Inconclusive" determinations were especially common among the 20 reports involving allegations of sexual abuse. Eight of these 20 reports, or 40%, were closed by the reporting provider with an "inconclusive" determination.

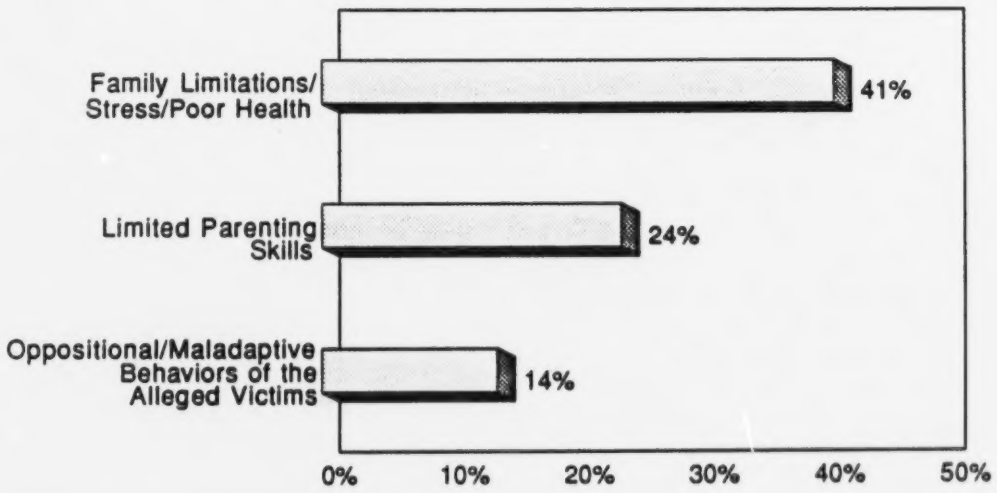
[5] Readers are cautioned that most programs utilized the OMRDD regulatory definitions for abuse and neglect in state-operated and -licensed programs in determining "confirmation." These regulations pertain to abuse or neglect by a program staff person or volunteer, not actions by a parent in a family situation. State statute and regulations provide a higher standard of harm in the definition of "endangered adult," which is used as the benchmark for the provision of a short-term involuntary protective services order (STIPSO) for adults in the community. State Social Services regulations define "endangered adult" as an individual age 18 or over who: (1) is in a situation or condition which poses an imminent risk of death or serious physical harm to him or her; and (2) lacks the capacity to comprehend the nature and consequences of remaining in this situation or condition (NYCRR, Title 18[B] §457.10 [a][1]). For the purposes of this report, the Commission is reporting the program's determination of its investigation. It is likely that these OMRDD providers relied on the OMRDD definition, rather than the endangered adult standard in Social Services law and regulations.

Family Stress and Common Problems

In responding to the Commission's survey, the reporting programs most often cited specific family problems, poor parenting skills, and family stress as contributing factors to the alleged abusive incident. Of the 70 surveys received (each related to one of the original 84 reports studied), 61% cited one or more of these factors (Figure 6).

Specific family limitations and stress, including the caregivers' own disabilities (intellectual, emotional, and physical), language barriers of caregivers, or poor health of family members were cited in 41% of the survey responses. Specific case examples in the Commission's sample well illustrated these family difficulties.

Figure 6: Familial Issues Contributing to Abuse/Neglect Allegations*
[N = 70]



*Data based on survey responses for 70 of the 84 reports. Categories are not mutually exclusive. In total, 61% of the responses cited at least one factor.

A young woman (age 26) reported to the nurse at her sheltered workshop that the previous evening her father had been angry with her and hit her with a mop handle. In response to the nurse's inquiry, the young woman's father admitted hitting his daughter, but he expressed much regret for his actions. The father, who is legally blind, also confided that since his wife died, he had found it difficult to manage the home and care for his daughter.

A young man (age 27) told the day program staff that his father hit him with a hairbrush. Although the young man was known to be physically and verbally aggressive at home, his father admitted that he had been under a great deal of stress and was "provoked" by his son's behavior. He explained that his wife was ill and that the family was also trying to care for another child with developmental disabilities in their home.

In many cases, families were applying physical discipline techniques which may have worked well when their child was younger, but which had become less effective as the child had grown to an adult.

A young man (age 34) reported that his father had hit him. The family readily admitted that the father and son had been fighting and that the father had punched the son in the face and thrown a can at him, resulting in some facial cuts and abrasions. Both the mother and father reported experiencing medical problems, and both confessed that they were not coping well with their son or their other three children who suffered from emotional problems, and who were also living at home.

Approximately one-fourth (24%) of reporting programs responding to the survey also cited inadequate or limited skills of family caregivers in coping with difficult or oppositional behaviors of the alleged victim, as contributing to the allegation. In many of these cases, families were still applying physical discipline techniques which may have worked well when their child was younger, but which had become less effective as the child had grown to an adult.

A young woman (age 33) showed a staff person, arriving at her home, six bruises on her leg which she alleged had resulted from a beating by her father with a belt. In discussing the incident with the young woman's aunt, the staff person learned that the young woman had indeed been beaten by her father because of bad behavior. Reportedly, the young woman had defied her father's authority and had been verbally abusive to her aunt and grandmother.

A mother called a staff person at her daughter's vocational program to report that she had resorted to biting her daughter's hand the evening before, as her daughter (age 39) would not release her grip on her [mother's] wrist. A home visit revealed that the mother was in poor health and that she frequently uses this biting technique to loosen her daughter's painful grip.

These cases, rooted in family difficulties and problems, also seem to have in common an absence of deliberate intent to harm on the part of the family member. Although the family member's action was usually inappropriate and sometimes quite violent and abusive, in most cases, a careful reading of the report revealed that the family member was employing discipline methods that he/she had long found acceptable or that he/she had admittedly overreacted out of embarrassment, fear, or frustration.

Few Confirmed Incidents of Overt, Intentional Abuse

In 35% of the confirmed reports, the family caregivers' responses appear to cross the line from well-intentioned, if ill-conceived, attempts at discipline to overt, intentional abuse.

In trying to understand more fully the "causes" of the familial abuse reports studied, Commission staff also took a narrower look at the 37 "confirmed" reports in the original sample of 84. In total, 65% of these confirmed reports related incidents where family limitations, inadequate parenting skills, or other family stressors were key factors in contributing to the abuse. In the remaining third (35%) of the confirmed reports, the family caregivers' responses appeared to cross the line from well-intentioned, if ill-conceived, attempts at discipline to overt, intentional abuse. Nine (9) of these 13 reports involved physical abuse; three involved sexual abuse; and, one related an incident of neglect.

As reflected in the case descriptions below, these reports reflected more violent and dangerous behaviors than most of the reports in the sample.

A young woman (age 25) refused to ride the bus home from her day program and ultimately staff had to arrange alternate transportation, as the young woman had tried to hit and kick the bus driver. Upon arriving at her home, the young woman refused to get out of the car, and her mother (in the presence of program staff) grabbed the young woman by the hair, pulled her out of the car, and then repeatedly punched her daughter on the head, neck, and back. During the entire incident, the mother continued to swear at her daughter, and she later admitted to staff that she had given her daughter "an awful licking."

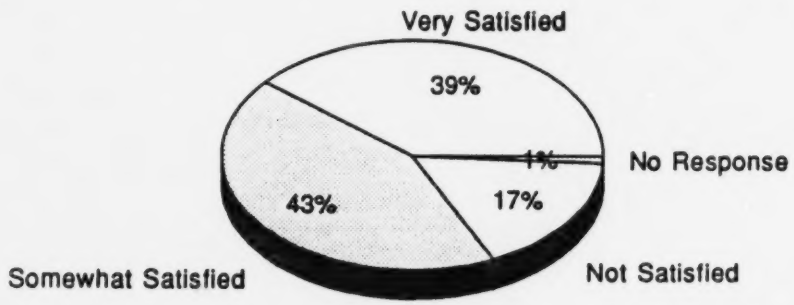
A young woman (age 21) spoke with the manager of her day program about an incident the previous evening, alleging that her mother had punched her in the eyes, twisted her arm, and stepped on her back. The young woman had two black eyes, scratches on her face, and bruises on her back. The mother acknowledged to the program manager that her daughter had come home from her day program screaming and throwing things and that she told her daughter that if she did not stop, she (the mother) would "kick the hell out of her." The mother reported that she knocked her daughter to the floor, pinning her down by sitting on her, and then slapped her in the face and eyes.

Adequacy of Investigations and Protective Actions

Many Problematic Investigations

Over half (60%) of the reporting programs responding to the Commission's survey indicated that they were less than fully satisfied with their ability to investigate the allegation. Forty-three (43) percent stated that they were only "somewhat satisfied," and 17% indicated that they were "not satisfied" (Figure 7).

Figure 7: Reporting Agencies' Satisfaction With Their Ability to Investigate the Allegation [N = 70]



Almost one-fourth of the reporting programs responding (23%) cited jurisdictional problems with local law enforcement and local Adult Protective Services agencies. Many reporting programs complained that once cases were referred to one or both of these agencies, they were not kept informed of important findings and developments. In a few instances, reporting programs also complained that law enforcement or Adult Protective Services agencies did not accept their referrals, noting the cases were not appropriate for their jurisdictional responsibility. Others (13%) commented that investigation efforts were severely limited because families would not cooperate with the investigation or accept needed support services. Still others indicated that the absence of needed support services to protect the alleged victim (9%), or the alleged victim's inability to provide specific details (4%), short-circuited their investigations.

Almost one-fourth of the reporting programs responding (23%) cited jurisdictional problems with local law enforcement and local Adult Protective Services agencies.

Representative comments of these reporting programs included:

We [the agency] were required to report the allegation immediately to legal authorities (district attorney, local police department) and, from that time on, they were in charge of the investigation. We lost our authority to conduct an investigation in a supportive/therapeutic manner and were left to await the results of the police investigation.

Mother is resistant to assistance; aggressive investigation techniques would result in loss of client contact.

Parent was not cooperative. Parent relocated and did not disclose her new phone number or address, even after many notes requesting this information.

The client is nonverbal, so verifying information is extremely difficult.

Comments from the reporting programs which had indicated that they were "very satisfied" with their ability to investigate the allegation attributed their satisfaction to the cooperation which they received from the family, other providers serving the alleged victim or family, and/or other local government officials. Some also credited themselves, noting that their proficiency and timeliness made the difference. Two survey comments were typical:

We [the reporting program] had the cooperation of local authorities that aided us in our ability to investigate.

[Our] actions to investigate the incident, inform pertinent agencies and protect individuals from incidents were prompt, well-documented and followed-up on.

Law Enforcement Usually Not Involved

Three-fourths of the reporting programs responding to the survey (77%) noted that they did not contact law enforcement officials for help. It should be noted, however, that approximately half of the reported allegations may not necessarily have warranted law enforcement notification. These reports (38 of 84 reports) did not reference a physical assault which caused an injury or an allegation of sexual abuse. While some of these allegations, due to the potential seriousness of the assault, may have been appropriate for law enforcement notification, clearly many were not.[6]

Many reporting programs, especially in New York City, stated they did not report more serious allegations to law enforcement officials because these officials typically did not take their complaints seriously, in part because the alleged victim would not make a good witness.

Notwithstanding this limitation, however, many reporting programs, especially in New York City, stated they did not report more serious allegations to law enforcement officials because these officials typically did not take their complaints seriously, in part because the alleged victim would not make a good witness. Among the few programs that reported contacting law enforcement (n = 16), only 31% indicated that they were "very satisfied" with law enforcement's investigation.

More typically, providers indicated that they were "somewhat satisfied" (31%) or "not satisfied" (31%) with the help they received, and most added their specific complaints.

Legal authorities took over the case and the agency lost authority. As a result, the agency was unable to provide support, and we are awaiting the results of the investigation.

The agency felt that the assignment to appropriate personnel [by the law enforcement agency] did not happen in a timely fashion. The agency was also concerned with the obvious lack of awareness of the MR/DD population on the part of the police investigator . . .

Reports from the providers indicated that allegations of sexual abuse were more likely to be referred to law enforcement officials, but that providers were slightly less satisfied with law enforcement's response to these cases. In total, 40% of the 20 reports of allegations of sexual abuse were referred to law enforcement officials, but only in 25% of these cases were the providers very satisfied with the follow-up intervention and investigation.

[6] Certain determination of law enforcement jurisdiction in all cases was not clear; however, 45% of the cases appeared to fall short of the criminal standards of an assault and to reflect an allegation of harassment which is classified in the State's Penal Code as a violation, not a crime. A small number of these cases involved an allegation of verbal abuse (7 cases), and 30 of these 38 cases involved an allegation of physical abuse not resulting in a reported physical injury. The distinction between acts of harassment and assault for some of these latter cases was not, however, always clear-cut. Some reports alleged *repeated* slaps, hits, punches, bites, etc., or acts of physical aggression which were potentially more serious and may have placed the individual at significant risk of physical or emotional harm.

Many Critical of Adult Protective Services

Many more of the reporting programs (66%) responding to the survey had contacted the local Adult Protective Services for help. Forty-eight (48) percent of the respondents indicated that they were only "somewhat satisfied" with the help they received from Adult Protective Services, and these respondents qualified their rating with specific concerns and problems that they encountered. Twenty-two (22) percent stated they were "not satisfied." While the programs reported a range of specific complaints, clearly the most prevalent concern centered on the quality of the Adult Protective Services investigations.

While the programs reported a range of specific complaints, clearly the most prevalent concern centered on the quality of the Adult Protective Services investigations.

Despite several requests by the reporting agency, the investigation was not completed by Adult Protective Services. Adult Protective Services contacted the mother by phone, questioning her [about the incident]; there was no full investigation. Adult Protective Services stated there was no point to investigate the incident because the client was unable to recall the date and time of the alleged abuse.

Many telephone calls were made; Adult Protective Services lost our report, and were reluctant to seek out the client for an initial assessment at home.

Adult Protective Services did not respond to numerous requests to investigate the home. They were extremely resistant to become involved and consistently insisted that the [OMRDD] BDSO handle the case.

Unless you keep calling Adult Protective Services, they almost never get back to you concerning follow-up.

Adult Protective Services will only get involved in life threatening situations. Given many factors and the family dynamics, this incident was not considered life threatening. Even when Adult Protective Services gets involved, they are not equipped to provide services to our population.

The DSS worker investigated by going to the home once and interviewing the client's mother. She [the DSS worker] accepted the mother's denial of abuse as fact. The DSS worker stated, " . . . they looked like nice people and had a nice home."

Despite the many criticisms of local Adult Protective Services, in some localities, their services were viewed very positively, and Adult Protective Services staff were seen as skillful intervenors in the admittedly difficult investigations of familial abuse of persons with developmental disabilities. In total, 10 reporting programs located in seven different counties (22% of those requested help) gave their Adult Protective Services high marks and much praise.

[The APS] response was prompt, and interviews and home visits [were conducted] within 24 hours.

APS made several home visits and follow-up calls.

APS was prompt in initiating [its] investigation and advocacy for follow-up services.

Most Reports Referred to Local OMRDD Offices

B/DDSOs enjoyed the highest satisfaction rating, with nearly half of the programs (44%) who sought their help, stating that they were "very satisfied" with B/DDSO services.

Reflective of the OMRDD .regulatory requirement that its state-operated and -licensed programs must report allegations of abuse and neglect to its regional B/DDSOs,[7] 89% of the reporting programs responding to the Commission's survey indicated that they had made this notification. B/DDSOs also enjoyed the highest satisfaction rating, with nearly half of the programs (44%) who sought their help, stating that they were "very satisfied" with B/DDSO services. Only 9% indicated that they were "not satisfied," one-third (31%) stated that they were "somewhat satisfied," and 16% offered no response to the question.

The most satisfied providers often complimented an individual staff person at the B/DDSO for being helpful, or they praised the timeliness of the B/DDSO's action ("BDSO helped to ensure [the] client's safety very rapidly and offered support services."). Criticisms of the B/DDSOs, in contrast, usually focused on their lack of responsiveness to referrals:

We asked [the BDSO] for a home visit [and] to follow-up and investigate immediately. The BDSO did not visit the home for six weeks.

The BDSO did not want to open a case because the client lived at home, and insisted that Adult Protective Services investigate. The Office of Protection and Advocacy at the Commission on Quality of Care was finally involved and assisted us in getting the BDSO to open a case.

It was also clear that provider agencies had variable expectations of their B/DDSO. For example, one provider stated that the agency was "very satisfied" because the B/DDSO had been supportive and provided guidance, while another, stating that the agency was "not satisfied," wrote, "Active intervention [from the DDSO] was not forthcoming, only verbal advice was given."

[7] As noted above, this regulatory requirement does not explicitly pertain to allegations of familial abuse and neglect. These regulations were drafted with a focus on allegations of abuse and neglect which occur within OMRDD programs. In practice, many providers have interpreted the regulations to subsume allegations of familial abuse and neglect, but some have not.

Figure 8: Protective Actions Taken*
(N = 84 Reports)

- Counseling Family 25%
- Counseling Victim 21%
- Family Monitoring 21%
- Monitoring Alleged Victim/Injuries 12%
- Exploring Community Placement 21%
- Received Community Placement (as of 11/91) 6%
- Respite "Offered" 27%
- Respite "Provided" 16%
- Change in Guardianship 5%

*Categories are not mutually exclusive.

Protective Services Limited

In 88% of the 84 cases in the sample, the reporting programs' reports indicated that they had taken one or more steps to protect the alleged victim from future abuse and neglect (Figure 8).

Counseling services to the family (25% of the cases) and the alleged victim (21% of the cases), as well as increased monitoring of the family situation through more home visits and communication with the family (21%), were the most common protective actions taken. Reporting programs less frequently indicated that they were stepping up monitoring of the alleged victim for injuries (12% of the cases) and/or of his/her behavioral status and medications (11% of the cases).

In 21% of the cases, the reporting programs noted that they were "exploring community placement," but it was not clear in the initial investigation report how many of these individuals actually received placement. In 27% of the cases, the investigation reports indicated that respite was "offered" to the family, although only in 16% of the cases did the investigation report state that a respite placement was actually provided to the alleged victim. Changes in guardianship were reportedly pursued in 5% of the cases, and alleged victims were encouraged to file legal charges in 2% of the cases.

More than half of the reporting programs responding (58%) also indicated that they were only "somewhat satisfied" (39%) or "not satisfied" (19%) with their ability to protect the alleged victim from future incidents of abuse.

Approximately two years after the studied reports were filed, the Commission followed-up on 17 cases where the providers had initially reported that they were exploring alternative residential placement for the alleged victim. This follow-up indicated that only five of these individuals had received a residential placement in the community, including one older woman (age 65) who moved to a skilled nursing facility. In nine cases, the provider agency reported that discussions and efforts to find an alternative residential placement stopped as the family or the individual was not interested or refused help. In the remaining three cases, an appropriate placement could not be found; in two of these cases, individuals remained at home, but in one case the individual's behavior problems became more severe, and she was admitted to a state psychiatric center.

Protection From Harm Often Not Assured

Reflective of the limited protective actions actually taken, more than half of the reporting programs responding (58%) also indicated that they were only "somewhat satisfied" (39%) or "not satisfied" (19%) with their ability to protect the alleged victim from future incidents of abuse (Figure 9). These programs offered a variety of reasons for their fears:

To a certain extent we [the reporting program] did manipulate day time program hours to protect the client. However, we had absolutely no control over evening and weekend hours . . .

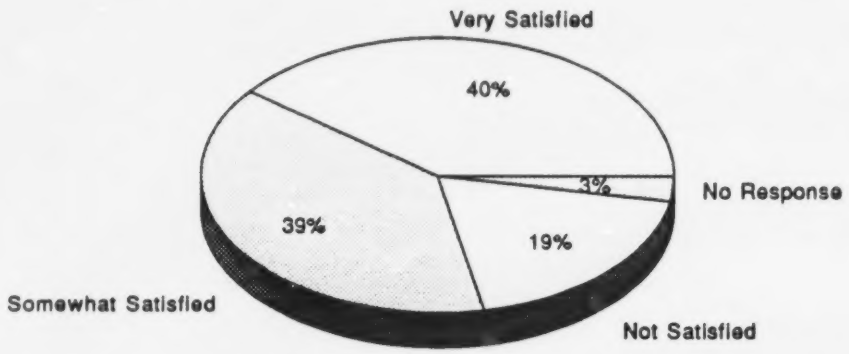
As this agency has no power to remove the client from the home, and Adult Protective Services is often unable to do so rapidly, we are not satisfied and must go to extraordinary lengths to safeguard the client.

We experienced a great deal of frustration in the unavailability of services from other support agencies.

Despite assurances, we [the reporting program] cannot guarantee that the father will not visit family members while [the client] is present.

Figure 9: Reporting Agencies' Satisfaction With Their Ability to Protect the Alleged Victim

[N = 70]



. . . 35% of the alleged victims had been cited in prior reports, and . . . 22% had been cited in at least one additional report in the year following the report included in the study.

The incidence of "repeat alleged victims" in the study's sample seemed to affirm the fears of many of these program providers. Thirty-five (35) percent of the reporting programs responding to the Commission's survey indicated that the alleged victim had also been cited in prior reports of allegations of abuse and neglect. Equally disturbing, 22% of the reporting programs responding to the survey stated that, in the year since filing the report included in the study, they had filed at least one additional report of possible abuse related to the alleged victim.

The limited "safety net" and many frustrations of providers in assuring more adequate protections for the alleged victims in most of the reported cases are also illustrated in specific experiences of several individuals described in Figure10. Most reporting providers proposed reinforcing of the safety net for alleged victims of familial abuse or neglect by providing services which were not offered by or presumably available to them. Over half of the respondents (57%) said that, if they had the option, they would have ensured a community residential placement for the individual involved in the report; 54% said they would involve the family caregivers in a parenting training or support group; and nearly one-third said that they would ensure respite and/or ongoing case management services for the family. Other specific proposals included: involving the client in late afternoon/evening/weekend recreation programs (26% of the respondents); engaging the family more actively in treatment planning for the individual (23%); and helping the family develop a larger social support network (20%).

Figure 10: Limited "Safety Nets"

A young woman (age 26) stated during a group meeting on "Stop Abuse" that her stepfather touches her breasts and vaginal area. Later, she told staff her stepfather had sexual intercourse with her. The day program reported the allegation to the police; however, it took the police one week until the police contacted the stepfather to begin the investigation.

Law enforcement officials would not share information with the agency until four months after the initial report. Ultimately, law enforcement dropped the investigation due to a lack of evidence, and the investigation's outcome was ruled inconclusive.

The agency reported that it adjusted the young woman's weekday daytime program hours to assure greater supervision; however, they expressed their frustration that they had little control over evening and weekend hours. The staff also reported that the family insisted that the young woman withdraw from the Stop Abuse Training, subsequent to their first contact with the police detective. The provider reports that support services were offered to the family, but the family refused these services.

* * *

A young man (age 31) with dual diagnoses of mental illness and mental retardation and a history of prior serious allegations of familial neglect, arrived at his day program with a large bruise on his forehead. He reported that he had not seen his mother or eaten in two days and that he was taking his seizure medications independently. The young man's aunt confirmed that he was home alone, and a telephone contact with his mother indicated that she wanted respite and a residential placement. The provider contacted the BDSO for emergency placement and Adult Protective Services for meals for the young man. Ultimately, after a five-day stay in the emergency room, inpatient admission was arranged at Bellevue Hospital.

The BDSO indicated that it would look for a more appropriate residential placement, and did offer the family a placement at the developmental center, but the family refused. The young man returned home from Bellevue Hospital, but, within a short time, there was another serious allegation, and he was admitted to a state psychiatric center in New York City.

* * *

A 27-year-old male attending a day program reported to staff that his father had slapped him, punched him in the stomach, and kicked him in the buttocks for losing his dentures. Although no bruises were noted, the young man's father admitted to hitting his son. The young man was offered residential respite services, but he refused them, wanting to return home. A meeting was held with the young man, his family, local Adult Protective Services staff, OMRDD B/DDSO staff and day program personnel. At this meeting the family refused offers of family support services, and Adult Protective Services closed the case. The provider agency reported that it would continue to monitor the situation and to provide counseling to the young man. OMRDD B/DDSO staff also gave the family a phone number to call if they wanted assistance.

* * *

A young woman (age 33) reported to a program staff person that she had been beaten by her father. The young woman's aunt corroborated the beating, but said that her niece was beaten after she defied her father's authority and was verbally abusive to other family members. The woman was found to have six bruises on her left leg from her father beating her with a belt.

The incident was reported to local Adult Protective Services, the alleged victim was counseled regarding her part in the incident, and she agreed she would try not to yell at her family. The provider reported that, when they had requested an alternative residential placement for the young woman, staff at the OMRDD DDSO reported there were no placements available.

* * *

A young woman (age 24) was crying when she arrived at program. Her lower lip was cut and she had an abrasion on her finger. The young woman claimed that her stepfather had hit her that morning when she was getting a sweater out of the living room closet. She reported that her stepfather was sleeping in the room and said that she had spit on him. The young woman's mother denied this account, but indicated that she had hit her daughter because her daughter was complaining about the lunch she was preparing.

The provider ensured some home visits and counselling for the family. Respite services were also "offered," but not rendered as the family never called to arrange a date and time. Within the year after this incident, the provider reported another very similar confirmed allegation of familial abuse to the Commission involving this young woman.

Conclusions and Recommendations

In New York State over 200,000 individuals with developmental disabilities are primarily cared for and supported daily by their families. Reported incidents of alleged abuse or neglect in these families are rare.

At the same time, however, this study confirmed that when allegations of familial abuse or neglect of adults with developmental disabilities do surface, they often reflect life circumstances that are very difficult for both the alleged victim and his/her family. This study also found that, in many of these cases, the failure to investigate these reports thoroughly and, more critically, to provide needed protective and support services, placed the alleged victims at high risk for recurring abuse.

In most cases reviewed, family members and the alleged victim want to stay together, but without dependable relief services, the reporting agencies believed that there would be a high probability of recurring abuse and neglect.

A central factor in most of the cases is the stress and difficulties many family caregivers encounter in coping with the maladaptive and oppositional behaviors of their adult sons and daughters with developmental disabilities. In reviewing the reports, the need for earlier primary prevention efforts for families who have extended their personal and financial resources to raise and care for their disabled relatives was evident.

Ready accessibility of parenting training programs for families when their sons and daughters are young children and responsive "help lines" which can respond with immediate respite to families where illnesses, deaths, and problems with siblings interfere with their caregiving role are critical. Unfortunately, at present there are not enough service providers in most localities which provide any of these services for families caring for children or adults with developmental disabilities.

Secondary prevention services, including ongoing non-emergency respite, support groups, and case management services for families, are also critical. In most cases reviewed, family members and the alleged victim want to stay together, but without dependable support services, the reporting agencies believed that there would be a high probability of recurring abuse and neglect.

Many providers also stressed the importance of ensuring immediate respite for the alleged victim, while these assessments are being conducted. It was also apparent that families respond more positively to offers of emergency respite — if they are available in pleasant, homelike settings *clearly established as a support for families*. Quite reasonably, most families will be resistant to services, if they perceive them as a vehicle for taking their son or daughter out of their home. There is a need for regular ongoing offers of respite to all families caring for adult relatives when things are going well, and not just making these offers in times of crises. *To truly support families, respite services should not only be crisis services.*

In a small percentage of these cases, there was an apparent need for an alternative living arrangement for the alleged victim. The need for OMRDD to take steps to ensure that these adults at high risk of recurring abuse and neglect are afforded appropriate alternate places to live is especially imperative now, as the state is moving to close several developmental centers and significantly reduce the census at others. These state priorities have placed a premium on community placements, and, unless explicit administrative priority and attention are focused on finding placements for these individuals at high risk for continuing familial abuse, they may wait for months or years to move to a safe and appropriate living arrangement.

In many respects, the governmental response to these allegations on the local level was also problematic, and these problems often contributed to the continued risk and suffering of both the individual and the family.

In many respects, the governmental response to these allegations on the local level was also problematic, and these problems often contributed to the continued risk and suffering of both the individual and the family. In particular, there seemed to be considerable contention between Adult Protective Services and local B/DDSO officials over which agency was primarily responsible for taking action.

Misunderstandings about the "real" limits of local Adult Protective Services in providing help, support, and protective services for the individuals with developmental disabilities allegedly abused or neglected, or their families, appeared to be at the heart of this interagency strife. In many cases there seemed to be disagreements about Adult Protective Services' responsibility to intervene in less serious allegations or to provide protective services if the adult was already a client of an OMRDD-operated or -licensed day program.

As reflected in this report, it is true that the threshold of harm or risk of harm (imminent risk of death or serious physical harm) for *involuntary* services from Adult Protective Services is quite high and often was not met by the cases the Commission studied. Social Services Law §473, however, clearly provides a lower threshold for initial Adult Protective Services intervention.

This law requires the local Adult Protective Services agencies to provide protective services "for individuals without regard to income who, because of mental or physical dysfunction, are unable to manage their own resources, carry out the activities of daily living, or protect themselves from neglect or hazardous situations without assistance from others and have no one available who is willing and able to assist them responsibly."

The law further delineates these services as including: (1) receiving and investigating reports of seriously impaired individuals who may be in need of protection, (2) arranging for medical and psychiatric services to "evaluate and wherever possible to safeguard and improve the circumstances of those with serious impairments," and (3) when necessary, arranging for "commitment, guardianship, conservatorship or other protective placement of such individuals directly or through referral to another appropriate agency, or for conservatorship or committeeship."

The Commission believes that a more accountable safety net must be assured for adults with developmental disabilities who are allegedly abused or neglected by their family caregivers. Integral to this safety net in many counties will be more forthcoming leadership, investigation, and intervention of these cases by local Adult Protective Services.

Additionally, this section of law, as amended in 1987, also recognizes that Adult Protective Services in the county should not operate as an island unto itself and mandates coordination and cooperation among local public, private, and voluntary agencies in carrying out this section.

> Each social services district shall prepare . . . after consultation with appropriate public, private, and voluntary agencies, a district-wide plan for the provision of adult protective service . . . . This plan shall describe the local implementation of this section including . . . the provisions made for the purchase of services, interagency relations, interagency agreements, service referral mechanisms, and locus of responsibility for cases with multiagency service needs (§473[2][b] Social Services Law).

Ten of the reporting OMRDD providers, and 22% of those who requested help from Adult Protective Services, indicated that their local Adult Protective Services agency came through with flying colors in fulfilling these investigative and protective roles and ensuring a coordinated local response in ensuring the support and assistance that was needed. Of note, these providers' comments were attributed to local Adult Protective Services agencies in seven different counties.

In many of the cases studied, however, the providers were disappointed in the help they received from Adult Protective Services. It was also apparent that, in almost all cases, Adult Protective Services did not provide specific protective services for the individual or ensure a coordinated county effort for a plan for the delivery of such services.

The Commission believes that a more accountable safety net must be assured for adults with developmental disabilities who are allegedly abused or neglected by their family caregivers. Integral to this safety net in many counties will be more forthcoming leadership, investigation, and intervention of these cases by local Adult Protective Services.

In its response to the draft report, the Commissioner of the Department of Social Services, Mary Jo Bane, noted that problems in the responsiveness of local Adult Protective Services had also been detected by an internal department audit and that a new comprehensive administrative directive (90 ADM-40) was issued on October 25, 1990 to address the problems noted. The Department also references formal Adult Protective Services case reviews and technical assistance to local offices as initiatives to address cited problems and concludes:

> Because of the aforementioned initiatives, we are certain that we have markedly improved the performance of the districts .... However, we acknowledge that there may be instances in which a district does not fulfill its responsibilities .... When these situations are identified, we urge provider agencies or your [Commission] staff to contact the Division of Adult Services, which will promptly investigate the matter and assure that any necessary corrective actions are implemented.

The Commission is again urging OMRDD and DSS to work together in ensuring that local Adult Protective Services offices and local B/DDSOs develop formal agreements for cooperation in cases of allegations of familial abuse and neglect involving adults with developmental disabilities.

As the Commission recommended in 1989 in concluding an investigation of the death of an individual with developmental disabilities in the care of a family surrogate caregiver (*In the Matter of Francis Helms*, June 1989), local Adult Protective Services and local B/DDSOs must also become more cooperative partners in responding to these reports. For the cases studied, many of the needed protective and support services for the individual are under the jurisdiction of the local B/DDSO and, in many other cases, B/DDSO staff hold essential expertise in interviewing adults with developmental disabilities that is critical to a comprehensive investigation.

In 1989, when the Commission first made this recommendation, OMRDD responded that the instant death case did not substantiate a statewide problem warranting a statewide action. This study of 84 cases emanating across the state, unfortunately, does confirm a statewide problem and, therefore, the Commission is again urging OMRDD and DSS to work together in ensuring that local Adult Protective Services offices and local B/DDSOs develop formal agreements for cooperation in cases of allegations of familial abuse and neglect involving adults with developmental disabilities.

Recommendations

1. The State Department of Social Services should ensure that its local Adult Protective Services agencies are clearly informed of their responsibility to investigate reports of alleged abuse and neglect involving adults with developmental disabilities by a family member and to provide protective services to the individual, as warranted, in cooperation with other local public, private, and voluntary agencies—regardless of the alleged victim's concurrent service provision by an OMRDD-sponsored day program or clinic.

2. The Commissioners of the State Department of Social Services and the State Office of Mental Retardation and Developmental Disabilities should issue a joint statement to their local offices (Adult Protective Services and B/DDSOs) requiring that they enter into formal cooperative agreements which will guide their response to reports of allegations of familial abuse and neglect of adult persons with developmental disabilities. At a minimum, these agreements should cover interagency cooperation on investigations and risk assessments, the development of protective services plans for individuals and their families, and periodic follow-up case reviews and risk assessments.

3. The NYS Office of Mental Retardation and Developmental Disabilities should ensure that its regulations clarify the responsibility of its state-operated and -licensed providers to report all allegations of familial abuse and neglect which come to its attention promptly to the local Adult Protective Services, the local B/DDSO, and in cases where the allegation may involve a criminal act, to local law enforcement. While recognizing that these providers should be shielded in many situations from direct involvement in investigations which could threaten their relationship with the alleged victim, B/DDSOs and Adult Protective Services should ensure that the provider is kept abreast with the status of the investigation and allowed an opportunity to contribute in developing any issued protective services plans.

4. The NYS OMRDD should establish a priority for development of several emergency respite beds in every B/DDSO which would allow for:

   - emergency respite for families and adults with developmental disabilities in times of crisis;
   - interim respite placements, when warranted, during the evaluation and/or investigation of allegations of abuse or neglect involving family members; and,

- short-term residential alternatives for individuals who can no longer safely live at home, while more permanent alternate living arrangements are pending.

5. Through participation in the NYS Citizens' Task Force on Child Abuse and Neglect, the NYS OMRDD should promote more effective primary prevention of familial abuse and neglect of adult persons with developmental disabilities by ensuring all new parents of children with developmental disabilities have opportunities to participate in positive parenting programs when their children are very young, and periodically throughout their childhood and adolescence.

Appendix A

NEW YORK STATE
DEPARTMENT OF SOCIAL SERVICES
40 NORTH PEARL STREET, ALBANY, NEW YORK 12243-0001

MARY JO BANE
Commissioner

(518) 474-9475

May 1, 1992

Dear Mr. Sundram:

We appreciate the opportunity to comment on your draft report, "A Review of Familial Abuse Allegations of Adults with Developmental Disabilities". We share your concern that the abuse/neglect of these impaired adults is a serious problem which requires the attention and cooperation of our Department, the Office of Mental Retardation and Developmental Disabilities (OMRDD), and where appropriate, law enforcement agencies. Our comments on some of the specific issues raised in the report are presented below.

1. One of the implications made by this report is that some local Protective Services for Adults (PSA) agencies (local social services districts) have failed to effectively respond to reports of abuse and neglect involving impaired adults. In response to this concern, please be assured that the Department is committed to assuring that all local social services districts promptly and effectively respond to reports of abuse and neglect of impaired adults and provide necessary protective services in accordance with State law and applicable regulations. To this end, the Department closely monitors the performance of local districts. Beginning in 1986 we initiated a case review process in which a sample of PSA cases were reviewed from each district to determine its compliance with the PSA standards set forth in Part 457 of the Department's regulations. Districts which were out of compliance with one or more of the standards were required to develop corrective action plans to address the identified deficiencies.

   One of the major findings of this review was that the staff of many local districts were unclear about their responsibilities to provide PSA to impaired adults who were being served by other agencies. This finding prompted the Department to develop a comprehensive Administrative Directive on the PSA eligibility criteria. This directive, (90 ADM-40), was issued on October 25, 1990, which is subsequent to the time period covered by your report.

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AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER

In 1989, the Department initiated a second round of PSA case reviews which we are still in the process of completing. As part of this process, fiscal sanctions are imposed against those districts which are determined to be out of compliance with one or more of the PSA standards. The withheld reimbursement is released once a district is able to demonstrate that it has implemented the appropriate corrective actions. The results of the current reviews indicates that the PSA performance of the districts has significantly improved since the initial case reviews were conducted.

In addition to the case review process, we have continued to strengthen the PSA program standards and to enhance our ability to provide technical assistance to local district staff. For example, this year we have started to provide specialized technical assistance to each district to enable us to address specific local service delivery issues. We also continue to improve our training curriculum for PSA caseworkers and supervisors. The topic of abuse and neglect of impaired adults is covered in a mandated five day training program called "The PSA Institute". This year we also are offering a two day training program for local PSA staff entitled "Adult Abuse in the Community: Detection and Intervention Strategies".

Because of the aforementioned initiatives, we are certain that we have markedly improved the performance of the districts with regard to the provision of PSA. However, we acknowledge that there may be instances in which a district does not fulfill its responsibilities regarding the provision of PSA. When these situations are identified, we urge provider agencies or your staff to contact the Division of Adult Services, which will promptly investigate the matter and assure that any necessary corrective actions are implemented.

2. We question the appropriateness of the heading on page 18 of the report, "Many Critical of Adult Protective Services". The body of the report indicates that only 22% of providers indicated they were not satisfied with PSA's response. An equal number indicated they were very satisfied with the efforts of the PSA program, while 48% indicated they were only "somewhat satisfied" with PSA. The partial satisfaction of many providers may not necessarily reflect on the performance of PSA staff since there are other factors, such as the availability of other support services, which have a direct impact on PSA's effectiveness in a particular situation.

3. In the footnote on page 10 of the report, you indicate that the definition of "endangered adult" is used as the benchmark for the provision of involuntary protective services orders for adults in the community. While this definition is the statutory standard for the issuance of a Short-term Involuntary Protective Services Order, (STIPSO), it does not apply to other legal interventions which may be pursued by a district on behalf of involuntary clients. These interventions include an Order of Protection pursuant to Article 8 of the Family Court Act and Conservator and Committee pursuant to Articles 77 and 78 of the Mental Hygiene Law.

4. We believe that we have already addressed the first recommendation contained in your report. As indicated above, on October 25, 1990 the Department issued an administrative directive, (90 ADM-40), entitled, "Protective Services for Adults (PSA): Client Characteristics". This directive provides the districts with a comprehensive explanation and discussion of each of the PSA eligibility criteria, with special emphasis on those situations in which a client is being served by other agencies. To assist district staff with the implementation of this directive, six regional technical assistance sessions were conducted by state staff in the Spring of 1991. In addition, we have continued our efforts to strengthen interagency cooperation for PSA through our training initiatives and the Consolidated Services Plan process.

5. Concerning your second recommendation, the Department's Consolidated Services Plan process already requires local social services districts to enter into written agreements with other public and private agencies concerning the delivery of services to PSA clients. Developmental Centers and community mental health services are included on the list of specific providers with which agreements should be developed. However, since the abuse, neglect and exploitation of impaired adults is such an important issue, we agree that it would be appropriate for the Department and OMRDD to issue a joint statement to the local districts and the Borough/District Developmental Disabilities (B/DDDSO) Services Offices on the need to ensure that substantive agreements are in place and updated if necessary.

6. We support your recommendation that OMRDD ensure that all allegations of familial abuse and neglect are promptly reported to PSA and the local B/DDDSO, and where appropriate, to law enforcement agencies. OMRDD should also advise its B/DDDSO's that local PSA staff will usually need their cooperation in conducting their investigation and planning for service delivery. In its role as case manager, PSA must rely on services available in the community to meet the special needs of these clients. We also concur that B/DDDSO and PSA staff should keep provider agencies informed about the status of investigations and involve them in the development of protective services plans.

7. We share the concerns of the providers interviewed for this report who indicated that there is a need for more supportive resources for families of developmentally disabled persons and additional residential options for persons who wish to leave abusive or neglectful living situations. PSA staff experience the same frustrations as other local service providers when there are insufficient resources to protect these clients.

In closing, please be assured of our continued commitment to improving the capabilities of the local districts to provide PSA. Please feel free to contact me or Acting Deputy Commissioner William E. Gould of the Division of Adult Services if you have any questions about our response.

Sincerely,

Mary T. Bane

Mary Jo Bane
Commissioner

Clarence J. Sundram, Chairman
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ELIN M. HOWE
Commissioner

THOMAS A. MAUL
Executive Deputy Commissioner

June 22, 1992

Mr. Clarence J. Sundram
Chairman
Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue
Albany, NY 12210

Dear Mr. Sundram:

Thank you for providing the Office of Mental Retardation and Developmental Disabilities (OMRDD) with the opportunity to comment on the paper drafted by your staff, A Review of Familial Abuse Allegations of Adults With Developmental Disabilities. We are pleased that you have chosen to address a form of abuse about which we share your concern. It is our hope that the issue, as well as the responsible entities for ameliorating individual problems, will be clarified.

Following are our comments concerning the contents of the report:

1. Page 26, top of page, proposes respite services be available to all families caring for adult relatives. OMRDD supports the availability of non-crisis, as well as crisis, respite. These services are available and continue to expand. We will follow-up to make sure that parents are informed of the respite services available in their catchment area.

2. Recommendation 2, Page 28, suggests that cooperative agreements be developed between DDSO's and APS statewide. We agree with your recommendation and will move to develop and implement such agreements throughout the state using the model currently in place at Long Island DDSO.

3. Recommendation 5, Page 29, might be more precise (given current developments) if it read, "Through participation in the "NYS Citizens' Task Force on Child Abuse and Neglect," OMRDD will participate in efforts to ensure that all new parents of children with developmental disabilities have opportunities to participate in positive parenting programs when their children are very young. OMRDD will also work closely with the Department

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of Health, through its outreach effort to all new parents, "Welcome to Parenthood," to ensure that parents of children with disabilities are made aware of opportunities to participate. Through the Memorandum of Understanding signed by both OMRDD and the State Education Department, OMRDD will work cooperatively with the SED to provide awareness for parents of opportunities to participate in positive parenting programs. The linkage of family support services to educational programs will be accomplished through the Committees on Special Education."

Again, thank you for allowing us to comment on your paper.

Sincerely,

Elin M. Howe

Elin M. Howe
Commissioner

EMH/EH

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